HIV/AIDS-related stigma felt by people living with HIV from Buea, Cameroon

Christoph A. Jacobi*a, Pascal N.J.I. Atanga*b, Leonard K. Bin*b, Victor N. Mbome*c, Wilfred Akam*d, Johannes R. Bogner*e, Siegfried Kropf*f and Peter Malfertheiner*a

aDepartment of Gastroenterology, Hepatology and Infectious Diseases, University Hospital Magdeburg, Magdeburg, Germany; bRegional Technical Group to Fight HIV/AIDS, Buea, Cameroon; cBuea Regional Hospital, Buea, Cameroon; dRegional Hospital Limbe, Limbe, Cameroon; eDivision of Infectious Diseases, Medizinische Poliklinik-Innenstadt, University of Munich, Munich, Germany; fInstitute for Biometry, University Hospital Magdeburg, Magdeburg, Germany

(Received 2 July 2011; final version received 7 June 2012)

The universal access to treatment and care for people living with HIV (PLWHIV) is a major problem especially in Sub-Saharan Africa, where the majority of HIV infected people live. However, equally important is the fact that HIV/AIDS-related stigma is recognized to be a major obstacle to successfully control the spread of this disease. In this study we measured the HIV/AIDS-related stigma felt by PLWHIV in Cameroon using “The people living with HIV stigma index” questionnaire developed by UNAIDS, International Planned Parenthood Federation and Global Network of PLWHIV/AIDS among others. A total of 200 questionnaires were anonymously administered to PLWHIV in the HIV/AIDS treatment center of the Regional Hospital Annex Buea in the South West Region of Cameroon by trained academics who were themselves PLWHIV. In this setting the major problems faced by the PLWHIV with regard to stigmatization and discrimination were gossiping and verbal insults, which was felt by about half of the interviewees. Equally important was internal stigma, half of the PLWHIV felt ashamed and guilty to be HIV infected. This is the first report of this kind in Cameroon. These results will help to better understand HIV/AIDS-related stigma in this setting and in turn will improve the quality of life of PLWHIV by promoting their acceptance by the community.

Keywords: Cameroon; HIV; UNAIDS; stigmatization

Introduction

Almost 30 years after AIDS was first described, developing countries are still facing devastating health, economic, and social problems due to the HIV/AIDS epidemic. Worldwide it is estimated that a total of 33.4 million people are infected with HIV, two-thirds live in sub-Saharan Africa (UNAIDS, 2008). In Cameroon, UNAIDS estimated that by the end of 2008, 540,000 people were living with the virus (national prevalence of HIV at 5.1% (15–49 years)). The prevalence in males is reported to be 4.1% and females 6.8%, 7.5% of pregnant women are infected. About 39,000 people died during that year and about 300,000 children have lost a parent or both parents in Cameroon due to AIDS (UNAIDS, 2008).

Since the 2000 International AIDS Conference in Durban, South Africa, titled Break the silence, stigma has been recognized as a major confounding problem in the HIV/AIDS epidemic. Early on, it was recognized as a key factor in fuelling the spread of HIV (Holzemer et al., 2007; Nyblade, 2006). Thus, UNAIDS reported in 2008 in a rather pessimistic view that HIV/AIDS-related stigma has continued to persist for over 25 years and constitutes one of the largest barriers to coping with the epidemic (UNAIDS, 2008). Different forms of stigma have been described including perceived and internalized stigma. Perceived stigma refers to people living with HIV (PLWHIV) awareness of negative social identity (Berger, Ferrans, & Lashley, 2001). Internalized stigma includes negative beliefs, views and feelings toward HIV/AIDS and oneself (Mak, Poon, Pun, & Cheung, 2007). In addition, the complexity of defining HIV-related stigma in part stems from its interaction with cross cultural differences, structural inequalities, discrimination by health care professionals and social processes (Van Brakel, 2006). Equally HIV/AIDS-related stigma may also be compounded by negative societal attitudes toward routes of HIV infection (e.g., sex work, injection drug use) and demographic characteristics (e.g., gender, ethnicity) (Herek, Capitanio, & Widaman, 2003; Reidpath & Chan, 2005).

One example of discrimination by health care professionals was recorded in a breast-feeding versus formula-feeding trial in Nairobi which screened over 16,000 pregnant women for HIV and found 14%, or over 2000, who were HIV positive. Of these, the trial enrolled only 425 patients into care because few

*Corresponding author. Email: christophjacobi@gmx.com
Christoph A. Jacobi and Pascal N.J.I. Atanga contributed equally to this work.
women returned, the rest were afraid of the stigmatization (Nduati et al., 2000). Especially in developing countries, PLWHIV experience strong stigma and discrimination. In these societies, many people are not only faithful but also superstitious. In connection with the lack of knowledge it favors the development of stigmatization and discrimination (Nyblade et al., 2003). As a consequence, HIV/AIDS-related stigma has enormous negative impact on social relationships, access to resources, social support network, and psychological well-being of PLWHIV. Lee, Kochman and Sikkema (2002) found a significantly greater relationship between severity of symptoms and higher levels of internal HIV/AIDS stigma in PLWHIV. In addition, they reported that the increasing access and availability of antiretroviral (ARV) treatment has reduced the prevalence of HIV/AIDS-related stigma and resulted in increased use of HIV testing and counseling services. Moreover, HIV/AIDS-related stigma hampers effective HIV-prevention activities (condom use, HIV test-seeking behavior, care seeking behavior) and is a barrier to diagnosis, quality of care provided to HIV-positive patients, and the perception and treatment of PLWHIV by communities, families, and partners (UNAIDS, 2008). Many in the HIV/AIDS community note that, decreasing HIV/AIDS stigma is a vital step in stemming the epidemic. Given this situation, it is critical that interventions that effectively reduce HIV/AIDS stigma be identified and implemented.

In 2005, the Global Network of PLWHIV/AIDS (GNP +), the international Community of Women Living with HIV/AIDS, the International Planned Parenthood Federation and the Joint United Nations Program on HIV/AIDS (UNAIDS) developed “The people with HIV Stigma index.” This survey aims to collect information about experiences of PLWHIV/AIDS related to stigma, discrimination and human rights in all aspects of life. These include private and personal matters as well as matters regarding employment, testing and legal issues (UNAIDS, 2005).

We used this stigma index in the capital city of Buea in the South West Region of Cameroon to measure the HIV/AIDS-related stigma experienced by 200 PLWHIV in the local HIV/AIDS treatment center of the Regional Hospital Annex Buea. Buea is a city with a population of 86,000 people, and a local HIV infection rate of 7.8%. The treatment center is supporting about 2000 HIV patients, three quarters of whom are females. By elucidating major causes of stigmatization with the help of these interviews, we know what to work on: the results of the questionnaire will be used to implement an HIV/AIDS anti-stigma project with schoolchildren in Buea.

Materials and methods
The Stigma index questionnaire “The people with HIV Stigma index” was used to measure the stigma felt by PLWHIV in Buea, Cameroon. The questionnaire comprises of questions related to all areas of life in relation to HIV/AIDS. It is a lengthy interview type survey with mostly closed questions with four choices to a question: never, once, a few times, or often. It was developed not only to generate answers to these important questions but also to get PLWHIV involved in this process. At the end, knowing the answers, programs should be developed with the aim to reduce stigmatization. The questionnaire was kindly provided to us by UNAIDS (2005). We received permission from the management of the HIV/AIDS treatment center and the Regional Hospital Annex Buea as well as ethical approval from the health authorities from the South West Region in Cameroon to conduct the interviews. We trained academics (HIV positive individuals) as interviewers on the background and rational behind this questionnaire and how to conduct the interviews. A representative sample of PLWHIV (in relation to the PLWHIV being treated in the treatment center) taking into account sex, age of patient, patient on treatment, treatment naive patients was selected under our supervision by the nurses of the treatment center for the interviews. Almost every PLWHIV being asked by the nurses to be interviewed wanted to participate in the survey, giving us their written consent. The interviews were conducted anonymously in a private setting, where no one else was able to listen to the interview.

Results
Over a period of three months from October to December 2009 we conducted 200 interviews with PLWHIV. Sixty-nine percent of the interviewees were female. Twenty-six percent (female and male interviewees) were below the age of 25, 37% were between 30 and 39 years and 22% were between the age of 40 and 49 years. Most of them, 58%, told us that they knew their HIV status between one and four years, 73% of the interviewees received ARV treatment. These proportions correlate well with the actual trends of the HIV infections in Cameroon.

In the following section, the major results from the “The people with HIV Stigma index” questionnaire are summarized (UNAIDS, 2005).

Stigma from other people
When talking about the different forms of stigma, stigma from other people had the biggest impact on
the PLWHIV. While almost none of the interviewees reported to be excluded from social gatherings, religious activities, or from family activities because of their HIV status, almost 60 and 30% said that they were being gossiped about and being verbally insulted, respectively. A minority reported physical harassment or assaults (Figure 1). While the reason for being gossiped about or being verbally assaulted was mostly because of the HIV status, the reason for the physical violence was not due to the HIV infection. More than 12% of the interviewees reported that they were psychologically pressured and their status was used against them. What is the reason why the interviewees think they are being discriminated? While 40% did not know the reason, about 1/5 think, that the people were afraid of getting infected or that they look sick with symptoms associated with HIV (Figure 2).

With respect of housing and work, 18% of the interviewees were forced to change their place of residence or were unable to rent accommodations, of these 30% said that it was because of their HIV status. Twenty-three percent lost their job at least once during the last 12 months; more than 40% think that it was because of their HIV status. On a positive note, only 3% of the interviewees were denied health services because of their HIV status.

Internal stigma

Apart from stigma from other people, the internal stigma is the second major problem in dealing with the disease: almost half of the interviewees felt ashamed or guilty and 40% blamed themselves. One in three interviewees reported to have low self-esteem, more than one in five blamed others for the infection (Figure 3). Because of their HIV status, one in four of the interviewees decided not to get married and even more decided not to have sex and did not want to have more children. Only a very minor proportion decided not to attend social gatherings or isolated themselves from family or friends (Figure 4).

Testing and support

Seventeen percent of the interviewees were forced to submit to a medical or health procedure, including an HIV test. Fortunately, denial of health insurance, arrests or disclosure was not a matter because of their HIV status. However, 12% reported that their rights have been abused because of their HIV status. One in three interviewees confronted, challenged or educated someone who has stigmatized or discriminated the interviewee. Almost 70% of the interviewees supported other PLWHIV emotionally or gave physical support (25%). Thirty-six percent of the interviewees think that they have the power to influence decisions for local projects.

With regards to the HIV test, almost half of the interviewees responded that they took the test because of HIV-related symptoms, around 25% just wanted to know, only a few because they were about to begin a sexual relationship or get married (Figure 5). Twenty percent were pressured to take the test. Only about 60% received both pre- and post-HIV test counseling.

Disclosure and confidentiality

Once the HIV diagnosis was verified, the next question to be answered by the patient was: should I tell somebody my diagnosis? Regarding the disclosure of their HIV status and confidentiality, there were huge differences between different groups of people. While a majority of the partners of the
PLWHIV knew about their HIV status, most of their friends, neighbors, and children in the family did not know their status. A similar situation was described by the PLWHIV in the workplace. About 20 and 10% of the PLWHIV responded that somebody told social workers and healthcare workers, respectively, about their HIV status without their consent (Figure 6). Surprisingly, 78% of them said that the disclosure of their HIV status gave them big empowerment.

What were the reactions, when the people first knew about their HIV status? Surprisingly, especially a minor proportion of the partner or adult family members were very discriminatory or discriminatory. The majority of the health care workers, social workers or other PLWHIV were supportive or very supportive (Figure 7).

Discussion

Apart from limited access to treatment and care for PLWHIV, HIV/AIDS-related stigma is considered to be a major problem in stemming the spread of HIV in Sub-Saharan Africa. Cameroon has an estimated average HIV prevalence of 5.1%. Even though this

![Diagram](image1.png)

Figure 2. Stigma from other people II.

![Diagram](image2.png)

Figure 3. Internal stigma I.
prevalence is low compared to other countries from the continent, where prevalence rates are as high as 25% (UNAIDS, 2008), HIV/AIDS stigma is a major problem especially in resource limited environments like Cameroon.

Research on HIV stigma has been limited by an imbalance in attention paid to HIV uninfected versus infected people, a lack of consideration of the mechanisms through which HIV stigma impacts on people, and an imprecise understanding of the psychological, behavioral, and health outcomes of HIV stigma. The first research in the late 1980s focused on assessing the extent to which HIV uninfected people felt prejudice toward and discriminated against HIV infected people (Pleck, O’Donnell, O’Donnell, & Snarey, 1988). As the epidemic evolved,
emphasis was shifted to target PLWHIV, their experience with stigma and the outcome (Kalichman et al., 2001; Parker & Aggleton, 2003).

Summarizing major aspects of the results of the “The people living with HIV Stigma index” interviews, we found that gossiping and verbal insults were experienced by a majority of the interviewees. Fortunately, physical violence was reported only by a minority of the interviewed PLWHIV in Buea. However, often the verbal insults are as painful and devastating as physical violence, since especially in Africa the social structure is centered around the family. Most of the time, the PLWHIV is verbally insulted by his or her own family member causing an even greater isolation. As a consequence, the patient fails to receive the necessary care or support, and this can make access to treatment even harder, if not impossible. When the PLWHIV were asked why they thought they were discriminated, they said: they do not know the reason (40%), it is shameful to have HIV (25%) and people are afraid of catching HIV from me (20%). Internal or self stigma was regarded

Figure 6. Disclosure and confidentiality I.

Figure 7. Disclosure and confidentiality II.
correlation between children’s belief that HIV could directly help the PLWHIV. For example, in a recent study from Thailand involving primary schoolchildren between the ages of 14 and 16, we found that more than half of the interviewees were the so-called “late presenters.” The HIV test was taken because they had symptoms which were typically HIV related. The fear of having a positive HIV result probably prevented these persons taking the test earlier. The disclosure of the HIV status gave most PLWHIV a great empowerment. The majority of the health care workers, social workers or other PLWHIV were supportive or very supportive, when they interacted with the interviewee. This gives hope, since studies in other countries showed that especially the health care providers were discriminatory toward PLWHIV. In a recent study, 80% of the nurses and 90% of the doctors behaved that way (Ahsan Ullah, 2011).

What can be done to reduce stigma? Education is often the first step in stigma reduction and is often combined with other strategies. However, it has been shown that the influence of education is limited because many stereotypes in society as a whole are resilient to change. The effectiveness of educational approaches can be increased if combined with other approaches, like having contact with PLWHIV and skill building. Thus, studies have shown that a combination of education, counselling, and contact are the most promising to reduce HIV/AIDS stigma (Bos, Schaalma, & Pryor, 2008; Brown, Macintyre, & Trujillo, 2003; Heijnders & van der Meij, 2006).

Currently, we are undertaking a stigma reduction program in secondary schools in Buea involving schoolchildren between the ages of 14 and 16. We are using different modes of teaching them, including material from Kidd, Clay, and Chiiya (2007). We are paying special attention to the problems and difficulties our interviewees experienced. We strongly believe that this kind of program, especially involving young people will help to reduce stigma and thus will directly help the PLWHIV. For example, in a recent study from Thailand involving primary schoolchildren, it was shown that there was a strong positive correlation between children’s belief that HIV could be transmitted through casual contact and their negative attitudes toward their HIV-affected peers (Ishikawa, Pridmore, Carr-Hill, & Chaimuangdee, 2011). Similar to Cameroon, in Thailand the number of children whose parents are living with HIV or have died from AIDS is increasing significantly.

This study is the first of its kind carried out in the central African country of Cameroon. These results will help us to better understand the HIV/AIDS-related stigma felt by PLWHIV in Buea. This in turn will help to improve the quality of life of these people by fighting stigma but also promoting their acceptance by the community.

Acknowledgements
We would like to thank Dr Gerd Eppel/GIZ Yaounde, Cameroon, and Mrs. Badini/UNAIDS, who kindly provided the UNAIDS “The people living with HIV Stigma Index” to us. We would like to thank our HIV positive academic trainers (Delphine Sindoh, Neba Bertha, Che Christopher, Angela Nwa Tangwa, Andreas Efengwa Tongvia, Ayuk Joseph Agbornyong, Sylvester Nzalla Ngomde, Chabiah Michael Foisangle, Doris Nnam Nyoh, Tal Stephen), without their help this project would not have been possible. We would like to thank the nurses and the social workers from the Buea treatment center for their help in selecting suitable PLWHIV to be interviewed by us. We would like to especially thank Merck&Company, USA and MSD, Germany who kindly supported the whole project. Without their generous support, we would have not been able to successfully complete this project.

References


